

Helping brain injury survivors and their families

By Jim McBride

McBride is the secretary and member of the board of directors of the San Diego Brain Injury Foundation. A car accident in 1987 left his 18-year-old daughter brain injured. She was comatose for nearly two years and spent the next eight years at home 100 percent disabled struggling to recover. She passed away in 1997 as a result of complications from the brain injury.

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Terri Schiavo, the Florida woman whose feeding tube was just removed, is a tragedy that illustrates the havoc caused by brain injury – families are torn apart, the legal and medical issues are complex, survivors struggle for years to recover some of what they lost, but the emotional damage lasts a lifetime.

Schiavo is expected to die soon, but tens of thousands of brain injured Americans still struggle to find and grasp the helping hand they need to awaken from their living nightmare.

When a brain injury occurs, it's as if a bomb exploded in the middle of a family. Loved ones are in a state of shock and confusion. They are immediately immersed in a medical emergency and emotional crisis that will change their lives forever. The subsequent journey toward recovery is long, complicated and uncertain.

Following a traumatic brain injury, patients receive trauma or emergency care, and then a certain percentage of survivors are eligible for rehabilitation programs such as the ones offered at Sharp Healthcare Rehabilitation Services in San Diego, Scripps Hospital in Encinitas and elsewhere. But typically, survivors are discharged directly to home after receiving medical care, often feeling they do not have adequate information about the range of issues they must now address – insurance, legal, financial, employment, educational, emotional and much more. In fact, a 1994 study conducted in New York City found that 87 percent of brain-injured survivors were discharged from hospitals directly to home.

While a variety of community resources are available in the San Diego area to help with this recovery process, two major problems exist: (1) state funding for services needed by those suffering from traumatic brain injury, or TBI, is inadequate; and (2) there is no well-developed system for linking existing community resources with the brain injury survivors. Consequently, those who need the services that are available don't know they exist and are not benefiting from them.

These are significant problems when you consider the number of people affected by brain injury. In San Diego alone, 11,000 people are affected by TBI every year, and according to the national Brain Injury Association, 1.5 million Americans will sustain TBI annually. By contrast, about 175,000 new instances of breast cancer occur and less than 50,000 new cases of HIV/AIDS are diagnosed annually.

At current funding levels, the service delivery system in California is unable to collect and organize the data needed to define the special needs of brain injury survivors, including treatment options, educational needs and support services. This information is needed to determine appropriate funding levels for programs and activities that should be developed and sustained. Individuals with TBI and their families need ongoing access to information about the consequences of brain injury and the recovery process, including dealing with pain and isolation, locating disability services, re-learning how to communicate, understanding behavior changes, dealing with memory loss and spasticity and finding answers to questions about legal matters, health insurance and more.

Meanwhile, there are existing community resources that provide housing and financial assistance, therapeutic physical therapy, community college education programs, disability programs, social support, activities and more – but it is a challenge for survivors and their families to locate the appropriate services while dealing with the devastating consequences of brain injury.

The San Diego Brain Injury Foundation, which this year celebrates its 20th anniversary, has emerged over time as a primary local resource for information, education and referrals to community TBI services.

The foundation produces a brain injury guide in Spanish and English, a monthly newsletter; staffs a telephone help line; hosts meetings for survivors, family members and professionals; and operates a long-term residential care home for severely brain-injured survivors.

Recognizing the need to link providers of community services with persons recovering from brain injury, the foundation designed a state-of-the-art, Web-based communication system (www.sdbif.org). The system serves as a portal to guide survivors and families to a single source of information where virtually any question will be answered, a comprehensive listing of community services will be available and emotional support can be fostered via chat rooms and other electronic meeting places. But without funding, this system cannot become a reality, and survivors are left to find help on their own.

Still, momentum is growing around the idea of strengthening the link between brain injury survivors and community services.

The California Traumatic Brain Injury Planning Project, a practical, outcome-oriented plan for services that meet documented needs of brain injury survivors, reports that survivors and family members cited the lack of information on brain injury, resources, services, etc. as the most frustrating barrier in the system. Essentially, survivors and family members need to know what is available and how to get it.

In addition, following a survey of the National State Head Injury Administrators, reported in the *Journal of Head Trauma Rehabilitation* (2001, v16, n1), the authors recommended that states should implement a registry of brain injured patients that is linked to needed services. While the authors were focusing on hospital and medical services, survivors also need information on a broad range of issues including insurance, rehabilitation, emotional, legal, financial, assisted living and other supportive services.

A sophisticated, interactive Web-based communication system would be a good start.

Until California provides adequate funding for services needed by those suffering from traumatic brain injury, and until funding is located for an interactive Web-based information and referral system, brain injury survivors and their families will struggle to locate existing community resources.

For now, the San Diego Brain Injury Foundation remains a primary local resource for information, education, and referrals to community TBI services.